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EDSA WEBINAR



Down Syndrome Regression Disorder

Datum: **Tuesday, 16 May 2023**, 17.00 – 18.00 CET, per Zoom

Speaker: **Jonathan D. Santoro, MD Bio**

Translation: Croatian, Czech, French, German, Turkish and Ukrainian
Registration

Link: https://us02web.zoom.us/webinar/register/9316830159137/WN_6axCoWaYQlykg3uukYWhIA

Down Syndrome Regression Disorder: An Emerging Clinical Entity Responsive to Immune Therapy

Neurocognitive regression in young persons with Down syndrome has been reported since 1946. This condition, often in individuals too old for autism spectrum disorder and too young for Alzheimer's disease diagnoses have remained under-diagnosed and under-treated historically.

Data from the Children's Hospital Los Angeles has identified that this condition may be caused by inflammation in the brain in persons with Down syndrome and is highly responsive to treatment with immunotherapy. This lecture will review the signs and symptoms of the condition and some of the emerging treatment data available.

Biography



Jonathan D. Santoro, MD Bio

Dr. Santoro serves as the Director of Neuroimmunology and Demyelinating Disorders Program and Director of Research for the Neurologic Institute at Children's Hospital Los

Angeles. He is also an Assistant Professor of Neurology and Pediatrics at the Keck School of Medicine at USC.

Dr. Santoro completed his undergraduate, masters, and medical degrees at Tulane University. He completed residencies in pediatrics and child neurology at Stanford University subsequently had sub-specialty training in neuroimmunology at Harvard Medical School.

Dr. Santoro is one of only a handful of national clinician-scientists who treats neurologic disorders associated with Down syndrome. He has been instrumental in identifying systemic vascular abnormalities in persons with Down syndrome and moyamoya disease, a rare stroke disorder which affects persons with Down syndrome 26 times more frequently than the general population.

Dr. Santoro also has clinical research expertise in neuroinflammation as it is related to cerebrovascular disease and neurocognitive disorders such as Down Syndrome Regression Disorder (DSRD), of which he spoken on internationally. In addition to his clinical and research activities, Dr. Santoro advocates for persons with disabilities at both the state and federal level through the American Medical Association and the American Academy of Neurology.

SAVE THE DATE: EDSA AGA 2023

Dear EDSA members,

We want to inform you that the next EDSA Annual General Assembly (AGA) will be held again as a presence event after three years of online meetings.

Date and place are important for you, so you can plan and organize your travels.

Date will be: **27, 28 and 29 October 2023**

Place: **Madrid, Spain** (in the premises of our member Down España)

We are very happy to be able to use the rooms of Down España and we are looking forward to seeing many of you.

All other data about agenda, program etc. will come later. We will also collect names of whom will attend. And give you some hotel recommendations and details about how to find the Down España Center.

Best regards.

Cora

NEWS FROM THE WORLD

BARBIE DOLL WITH DOWN'S SYNDROME LAUNCHED BY MATTEL

Firm partnered with US charity and medical experts to create part of 'most diverse and inclusive doll line



Barbie is launching its first doll with Down's syndrome in an effort to help more children find a toy that represents them.

Mattel bosses said they wanted to bring out the doll to "enable all children to see themselves in Barbie". They partnered with the National Down Syndrome Society (NDSS) in the US to bring the product to market.

The move was welcomed by charities, with Carol Boys, chief executive of the UK Down's Syndrome Association, saying: "Children in our community will be able to play with a doll that represents them."

Ellie Goldstein, a British model with Down's syndrome who has appeared in a campaign with the new Barbie, said she was "so happy" to see the new doll. She added: "Diversity is important to me as people need to see more people like me out there in the world and not be hidden away."

Mattel said it consulted the NDSS and medical professionals to inform the design process, introducing a new face and body sculpt to be more illustrative of women with Down's syndrome, including a shorter frame and a longer torso.

Guided by the NDSS, the doll's pink pendant necklace with three upward chevrons represents the three copies of the 21st chromosome, which is the genetic material that causes the characteristics associated with the condition.

The chevrons, or arrows, represent "the Lucky Few" who have someone with Down's syndrome in their life.



Dolls from the Barbie Fashionistas line. Photograph: Jason Tidwell/Mattel

It will go on pre-order from Tuesday from the toy store Smyths. The doll is part of the Barbie Fashionistas line, which was launched in 2022. It also features a Barbie with a prosthetic leg, a Barbie who uses a wheelchair, and male dolls that are thinner and less muscular.

Mattel has described this collection as its “most diverse and inclusive doll line, offering a variety of skin tones, eye colours, hair colours and textures, body types, disabilities and fashions, to inspire even more stories”.

In recent years, Mattel has launched more inclusive Barbie lines, including one inspired by real-life women who have upended societal norms. In 2017, it released a doll [wearing](#) a hijab, modelled on Ibtihaj Muhammad, a fencer who became the first American to compete and win an Olympic medal wearing the garment.

“It was an honour working with Barbie on the Barbie doll with Down’s syndrome,” said Kandi Pickard, the NDSS president and chief executive. “This means so much for our community, who for the first time can play with a Barbie doll that looks like them.

“This Barbie serves as a reminder that we should never underestimate the power of representation. It is a huge step forward for inclusion and a moment that we are celebrating.”

The doll’s puff-sleeved dress pattern features butterflies and yellow and blue colours, which are symbols associated with Down’s syndrome awareness.

Source: The Guardian, April 25th 2023

NATIONAL DOWN SYNDROME SOCIETY

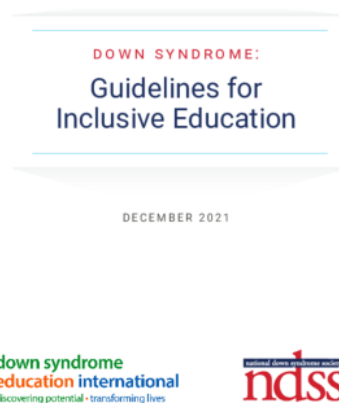
INCLUSIVE EDUCATION GUIDELINES FROM USA

Down Syndrome: Guidelines for Inclusive Education is the first document of its kind in the United States. The document addresses the education settings that support students with Down syndrome, covering the period from early intervention and primary education through secondary and through higher education, with the primary focus being K-12 students.

These guidelines draw on recommendations developed by an expert working group of a United Kingdom All Party Parliamentary Group on Down Syndrome (APPGDS), first published by the APPG in 2012.¹ The report is available at: <https://go.dselink.net/appg-education-report>

The National Down Syndrome Society (NDSS) and Down Syndrome Education International (DSEI) assembled a working group to adapt the APPGDS recommendations for the U.S. early intervention, preschool and school systems. The Guidelines Working Group includes several members of the NDSS Inclusive Education Task Force, a group of volunteers with a range of expertise and experience, dedicated to improving the lives of individuals with Down syndrome through the promotion of inclusive education.

[Download inclusive-education-guidelines](#)



NEW OPPORTUNITY FOR EDSA MEMBERS

ZERO PROJECT CALL FOR NOMINATIONS 2024



Independent Living & Political Participation, and ICT

Dear Edsa Members,

We hope this email finds you well. Exciting times are ahead of us, the Zero Project Call for Nominations 2024 (#ZeroCall24) opens in less than seven days on Monday, May 08, 2023!

This year we want to highlight again that the Zero Project and its Awards are open to all; projects big and small; projects from all around the world; be it a NGO, DPO, a school, an individual, a company, government, ministry, city, municipality, or a startup.

All disabilities; all continents; all are welcome at #ZeroCall24.

Below you will find all the key details to the Zero Project Call for Nominations 2024:

TOPIC

The Zero Project Call for Nominations 2024 will be focused on Inclusive Education, and ICT. More details on the subtopics and their definitions can be found at: <https://zeroproject.org/zerocall24>

DEADLINES

The Call for Nominations opens on Monday, May 08, 2023 and closes on Sunday, June 18, 2023.

APPLICATION QUESTIONS

Information is power. We want all nominees to be prepared for #ZeroCall24. [Download the questionnaire by clicking right here](#), which will allow you to best prepare your nomination ahead of the launch on Monday, May 08, 2023.

WEBSITE

The #ZeroCall24 website with all pertinent information is as follows: <https://zeroproject.org/zerocall24>

ONE PAGER

The Zero Project has prepared a one pager about #ZeroCall24, which we encourage you to share with your network. You can [download the one pager by clicking here](#).

QUESTIONS?

The Zero Project looks forward to receiving numerous applications from around the world and remains at your disposal with any questions or query you might have: office@zeroproject.org

Warmest regards, The Zero Project Team

MAKE THIS NEWSLETTER REALLY YOURS!

Have you got any news that we could publish in EDSA newsletter? Please send us any information you would like to announce and we shall be happy to disseminate it all over Europe!

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